

## FLORIDA CHAPTER

## NATIONAL HEMOPHILIA FOUNDATION, INC

January 23, 2002

Jo Anne B. Barnhart, Commissioner  
Social Security Administration  
PO Box 17703  
Baltimore, MD 21235-7703

Dear Commissioner Barnhart:

I am writing on behalf of the Florida Chapter of the National Hemophilia Foundation. We are very concerned about the proposed changes to the Social Security Disability hemophilia regulations.

First, we encourage the effort to change the adult listing (20 CFR 404). As written it does not reflect the treatment options that are available to person with hemophilia and other bleeding disorders today. In order to meet the current listing a person with hemophilia must undergo transfusions. This is obviously out of date and an inappropriate measuring tool.

The proposed regulations require "bleeding despite prophylactic factor replacement". Requiring prophylaxis is again an inappropriate measuring tool as that is not the treatment prescribed by many physicians. This is true especially for adults with bleeding disorders. Although many will infuse factor prior to events that they believe would lead to a bleeding episode such as sports activities, others only infuse when needed, once they have symptoms of an active bleed. Because of concerns of "capping out" their insurance or out of pocket expenses, many cannot afford to use factor on a prophylactic basis.

I realize that even if a person does not meet a listing they may still go through the process and be determined disabled. This usually takes considerably longer causing considerable hardship on the families involved. Creating a listing that better reflects hemophilia treatment or effects on the body would greatly help to reduce the time and expense of the disability process.

Also, the proposed regulations state that there must be one month between bleeding events. This is not clear. This requirement only makes sense if it is interpreted to mean one month between identical bleeds, such as 2 bleeds into the left elbow and not interpreted to mean one month between an elbow bleed and a knee bleed. It is not unusual for an individual to experience two very distinct and debilitating bleeding episodes in one month. Sometimes one bleeding episode can lead to another very unique and severe episode. A bleed in one knee may cause an individual to overcompensate and put more weight on the opposite leg and cause an ankle bleed.

Thank you for your consideration,

*Natalie Philipson*

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